

Iowa Autism Council Meeting Draft Minutes
June 11, 2014
Meeting minutes taken by Beth Buehler-Sapp

Present: Steve Muller, James Curry, Linda Wessels, Jim Mumford, Laura Larkin, Steve Johnson, Alyson Beytien, Theresa Croonquist, Rachel Heiss, Wendy Trotter, Tara Underwood-Levin, Jeffery Jennings, Angela Logsdon, Sean Casey and Beth Buehler-Sapp.

Absent: Matthew O'Brien, Becky Harker Andrew Waldschmitt, and Mary Jackson,

Via ICN: Josh Cobbs, Jan Turbes and

Guests: UIHC—Leslie Huber, Erika Hertel, & Peggy Swails. Hills & Dales—Marilyn Althoff, & Laura Keehner. and Northwest AEA-Brenda Langstraat-Janisch

The meeting was called to order by Steve Muller, Chair and we went around the room and did introductions.

There were 3 guests there from CHSC at UIHC who work with the WRAP Program. This multi-tiered program provides each client with a nurse practitioner, registered nurse, and a family navigator (social worker).

There were 2 guests there from Hills & Dales, a residential facility from Dubuque, Iowa.

RTI – Response to Intervention is intended to provide more supports to struggling learners prior to them reaching the point where they are eligible for IEP (Individualized Education Plan) services. Iowa utilizes RTI due to the fact that Iowa is a non-categorical state.

Steve Johnson mentioned the standardization of codes that is taking place and said he will put together a list for the group to review. Hopefully this will be available at the next meeting in September of 2014.

The council members spent a few minutes reviewing the minutes from November 13, 2013 the last meeting which was held as the meeting scheduled for March had to be cancelled due to multiple conflicts. James Curry made a motion to pass the November 13, 2013 meeting minutes. Steve Johnson seconded the motion, minutes passed.

HCBS Rules and Federal Directives

Steve Muller asked to review the “HCBS Rules and Federal Directives” by looking at the handout titled, “Home and Community Based Services Settings”. Laura Larkin said DHS is providing training statewide to providers and that the IME website outlines choices and waiver services for eligible individuals. Sometimes there are challenges between what an individual wants and what their family members want for them. There is a task-force studying this and their questions are, “Where’s the gap? and What are the opportunities?” Steve Johnson mentioned that occasionally there are problems when an individual is committed to a hospital while in crisis status and may wait a long time for an opening in an appropriate residential facility. “Hospitals shouldn’t be the safety net.”

Alyson Beytien explained that most providers don’t have the necessary skill set. It’s almost impossible for providers to have all of the various resources available to make community living an option. She’s been through Out of State placement, In State Institutionalization, etc. An appropriate environment, appropriately trained staff, and exceptions are needed in order for an option of 24 hour care. Hills and Dales in Dubuque is a rare example of such a provider. This is great and we need more of these.

Josh Cobbs opened up discussion to talk about options to avoid hospitalizations. Steve Johnson mentioned that Woodward and Glenwood had long been stable options in their communities. Two downsides are that these facilities typically have these individuals residing there for a lifetime so openings are not plentiful and that there has been some state policy initiatives to lesson the numbers of these types of lifelong, more restrictive placements.

On top of the basic stay costs all placements add supplemental appropriations of what is needed to function. This can be up to 2 times what providers have available.

Rachel Heiss talked about her son as a youth going from the residential facility where he lived to the Center for Self Injurious Behavior for assessment run by Dr's Walker and Sassoo. This was extremely effective and eliminated severe behavior. Due to the cost/burden of transporting individuals to such a facility there needs to be more availability. Particularly these providers to go out to the clients to provide such services. Especially for those living in rural areas where services don't exist.

Sean said that the Center for self injurious behavior is still operating and has phenomenal documented results but has a long waiting list. Typically there are no funding streams for travel of services.

The consensual opinion of the group is that Susan Smith from Woodward State Hospital who used to be a council member could speak much better as to the possibilities of sending a crisis team out to the patient.

James Curry suggested that a crisis team could go out to where a person was discharging from an ICF-ID to set up plans for the patient. An on-call person, rather than an entire team would probably be more feasible and cost effective. A plan needs to be set-up for the person discharging from a hospital for crisis intervention and going back to a residential facility. James suggests 13 regional teams to get training, things are already in place to disseminate information.

Alyson likes these ideas but thinks that long travel to provide services is not feasible.

Laura Larkin – Also with HCBS placements sometimes the linear focus of services isn't helpful. It's not just that we need other services but rather more across the board dispensation to pieces of services available.

James Curry suggested that the council think collectively about having Susan Smith come and present to the council regarding these possibilities. Steve Muller told the group that Susan is part of the current workgroup/task force studying this topic.

The most obvious problems that occur often are that staff hired for positions to work with these types of clients. Typically they are paid about \$10 an hour, there's approximately a 50% turnover, and there are extreme behaviors which the person must deal with. The state says it wants fewer persons at facilities such as Woodward or Glenwood.

Sean – "It is safe to say that we don't have enough providers." "There are not enough services available to support these people well." Josh – "If the service is the service, Why is the rate different based on location?" Room & board are not covered under the HCBS waiver but are covered if in an ICF-ID facility placement.

Waiver services are somewhat different from ICF-ID reimbursement rates. A benefit to ICF-ID is that families appreciate the security of knowing that the institutionalized family member is permanently cared for. This is especially important to family members in case they should pass away before the patient does and then they can feel secure.

Autism Support Program (ASP)

Autism Support Mandate – Tried to get this to passed but failed. \$2 Million dollars in funding to provide 1 on 1 ABA treatment for eligible children who are under the age of 9, must be at 400% poverty level or higher, and must not have insurance coverage for this. This was started April 1st and goes through June 30th. On July 1st (new fiscal year) 3 million dollars in new money will start but the remaining original funding will carry over to be available for year 2 (July 1, 2014 to June 30, 2015)

Prior to our June 11th meeting there had been 10 applications submitted for this program.

3 applicants are currently receiving services.

2 applicants are in the process of getting approved.

2 applicants were denied because they were receiving Medicaid.

1 applicant was over the financial limit.

1 applicant was over the eligible age.

These funds are intended to pay for costs within the education system, doctors and other professionals.

Steve Johnson assured the council that this program which is run through Magellan is highly regulated.

CHSC's wrap has been accessed all over Iowa and they want to make this program more available statewide.

Trying to find the folks that need the services. James asks, "Is there anything the council can do to help get the word out?" Laura, council members can access the Magellan Autism Support Website and the UIHC website as well and forward that information out to their contact lists.

Josh mentioned that the Pearce Center in Sioux City refers it's residents to UIHC specifically because of the family navigator person being part of the services provided in the WRAP program. There are also 2 full-time staff available to help families fill out applications for the WRAP program.

ASI (Autism Society of Iowa) – A Day on the Hill. This event is a great way to get the folks needing services in front of the legislators and groups who have the decision making/persuasion abilities to make choices that help them.

Jeffrey Jennings states, "I have seen too much replacement or transition of the providing of services."

Alyson recommends a resource which is listed on the Autism speaks website, the 1st 100 day kit. This explains how diagnosis is given and that it will have a lifelong impact.

Lin explains that when her son was diagnosed 10 years ago there wasn't as much visibility and now, "People are out there navigating waters you're never even thought of." At that time the Department of Education would provide an Early Access Parent Consultant, "Is that still the case?" Yes Rachel mentioned that interaction with other parents is also very helpful. They can answer lots of questions and also provide you with general camaraderie and support. It's overwhelming and unfamiliar to families when the diagnosis is new to them.

Action Steps

When a state issued a directive to add a mandate to existing insurance plans it only affects 1 out of 3 to 4 persons.

Jim Mumford says, "As a regulatory agency the Iowa Insurance Division can't mandate or support anything. We can only do what the legislature tells us to.

Rachel recalled that 10 years ago the Iowa Psychological Association Mandate included 6 diagnosis.' Autism, PDD (Pervasive Developmental Disorder), BiPolar, Schizophrenia, Manic Depression, and Depression.

In 2010 when the legislature mandated adding mental health service coverage to existing state employees coverage, 100,000 lives were impacted. Would a legislator or two be interested in using this as a platform. Cost figures coming in related to this mandate show that doing this did not break the bank. James says this sounds like easing the legislature into the idea of expanding the coverage (not just state employees).

Sean said he would expect the insurance companies to want to look at effectiveness data, how much money was spent, and sustainability and to make a very cogent argument.

Alyson says cost and number of kids provided services to information is available. In the states of Florida, Oregon, & Michigan insurance companies would rather defend lawsuits than to pay out the costs for services.

Rachel stated that progress is sometimes extremely slow with the drip, drip, drip, drip, drip method.

James asks what's the process? Do we propose to the Governor's office that the Iowa Autism Council host a conversation looking at what has happened worldwide?

Josh Cobbs says he would be in favor of talking to other states that have done this before we rush headlong into this. Sean Casey suggested that maybe we could have a University study/track these results and report to the council. When asked if there would be funding available to pay for this Sean said he could not speak on behalf of the Department of Education.

Leslie Huber, guest from chsc/uihc says that besides having data, having actual family stories and council input is very valuable.

Thomas Mayes from the Iowa Department of Education came to introduce himself to the council and express that he is available for inquiries if desired. Rachel Heiss asked Thomas, Are there any statisticians on your staff? Thomas said yes, there are some folks of this nature here at the department.

Thomas reminded the council members that they can represent themselves (i.e. Bob Smith) but not as members of the Iowa Autism Council. An individual cannot speak on behalf of the council. Persons contacting any politician of which they are not their constituent would not be able to do this unless they are a registered lobbyist.

Over representation was mentioned as in the example where an individual with ASD gets into perhaps legal trouble and they then identify that they have a disability. These needs should have been identified much earlier in the process.

Steve Muller asked, "Is there general consensus that we're going to continue to think about approaching the lobbyist? Sean Casey, Wendy Trotter, and Phil Casey (DE lobbyist) would need to have a discussion.

Josh – Do you know about the website work done and the outcomes. James – Looks at where we fit with other resources or creating a stand alone resource.

Do you start by listing providers?
What do you need to know about them?
Do you create a new website?

Steve Muller, "Would one or two council members work on looking at the basic information the council could make available. Tara Underwood-Levin and Angela Logsdon both volunteered to work together on this.

Josh – What type of housing is available in the state for individuals with Autism and where are these located?

James – Where do we get started? Laura – Information might be hard to access? (Facilities OI license, RCI type, and Inspections & Appeals listing.)

Josh – For residential living there is a 5 year waiting list. Where are the waiting lists? Do we have enough pipeline? Don't think so, How can we build on the pipeline?

Josh, Alyson, and Laura agreed to form a committee to work on the housing subject.

Tara Underwood-Levin said she would send out an e-mail to the wrap teams and that they would compile a list of housing choices and send to Josh, Alyson, & Laura. Josh will include Rachel on all of these e-mails while she is unable to actively participate at this time.

Josh said "Recommendations were made for what needed to be included in the ASD waiver."

Rachel said waiver assessments require an adaptive function along with an IQ test. Eligible individuals must have an IQ score of less than 75. An individual may have a normal IQ but have adaptive deficits.

Is it feasible to expand the ID waiver or create a new waiver? Steve Muller asked, "It is possible to rewrite a waiver but extremely difficult to do so?"

Waivers

Intellectual Disability Waiver

Children's Mental Health Waiver

Brain Injury Waiver

Health & Disability Waiver

Josh – What are we missing out of the Bevy of Services provided within these waivers?

Rachel doesn't think that when she wrote for waiver assessments that it specifically said Autism. She is going to review her previous notes and see what documentation she can provide to the council. Rachel also remembers that each family could work with an Early Access person from the Department of Education and wonders if this is still an option.

Sean Casey e-mailed Betsy Lin, Early Childhood Consultant at the DE and she responded that connecting with an Early Access Consultant is still an option for families with children in the 0-3 age range who are experiencing difficulties.

James suggests a Review of Language 1st to see if something else needs to be done. Rachel Heiss agreed to work on this.. When Rachel is done with her review she will send a draft to Beth to send out to the entire council for review.

James Curry made a motion to adjourn the meeting and Lin Wessels seconded the motion.